Update on the HSCIC's progress on implementing the recommendations from the data release review

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Contents

Purpose

The purpose of this paper is to provide the HSCIC Board with an update on progress against recommendations made by Sir Nick Partridge following the *Review of Data Releases made by the NHS Information Centre*[1]*.*

Progress

Overview of Progress

In the previous update to the HSCIC Board, strong progress was evidenced against six of the recommendations (recommendations 2, 4, 5, 6, 7 and 9) and these can be regarded as having been delivered at the point of reporting with only minor elements, if any outstanding.

Most notably since the last Board meeting, the backlog of data requests (applications for data received prior to August 1st 2014) has been cleared. There remain a few complex cases being dealt with, especially from the research community, where it was not made clear that applications were being closed. Discussions are ongoing with applicants about these.

Recruitment to the permanent DARS structure is ongoing and resources are now being focused on the applications received in the period between August 1st 2014 and January 31st 2015. Service standards are now being applied to all applications received from February 1st 2015. To date, all applications received since February 1st have been delivered to agreed service levels. Further information on these are provided below.

Three recommendations (1, 3 and 8) were identified as still requiring work. These recommendations relate to the deletion of data following the expiry of agreements; establishing a permanent audit function and implementation of secure access to data.

Work has progressed considerably on these, with clear plans in place for progressing the data deletions work and establishing the audit function, however they have not yet been completed. Further information on these items are provided below and a paper on progress against providing secure access to data is provided in Annex C.

Details of progress against each of the specific recommendations are provided below.

As part of its 2014/15 audit programme, The Health Group Internal Audit service, responsible for providing independent assurance to DH and its arms length bodies, is currently undertaking an audit of the progress against the recommendations. The outcome of this audit will be reported to the HSCIC Assurance and Risk Committee upon completion.

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[1] PwC for the HSCIC, *Data Release Review*, 2014 available at http://www.hscic.gov.uk/media/14246/HSCIC-Data-Release-Review-PwC-Final-Report/pdf/HSCIC_Data_Release_Review_PwC_Final_Report.pdf especially pp. 71-74.

Progress on Data Applications

Historic Applications

As of 31st January 2015, the backlog of applications received prior to August 1st 2014 has been cleared. There remain a few cases, especially from the research community, where it wasn't made clear that their applications were being closed or the reasons for this, and the HSCIC is in active discussion with the applicants to resolve these.

The mechanisms for accurately measuring performance against SLAs were only introduced for all applications received since February 1st 2015. As such there are a number of applications received between August 1st 2014 and February 2015 that are not subject to SLAs.

Resources are now being focused on clearing these applications, with the aim to complete this work by 31st May 2015.

The table below provides a breakdown of progress against these applications (as of 18/03/15):

Total applications received (01/08/14 – 31/01/15)	**395**
Applications closed or completed	280
Applications remaining	115
Of which with customer	32

A further breakdown of these is available in the dashboard in Annex A.

Implementation of Service Level Agreements

Service Level Agreements (SLA's) have been implemented for all applications for data received since February 1st 2015. These range from 14 days for standard applications to 60 days for complex applications.

As of 18th March, there are 72 applications for data that have passed initial triage[2] and are currently being processed through DARS. 13 applications have been completed and 36 applications have been rejected.

The table below provides a breakdown of these applications in relation to their SLAs

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[2] Applications for data are triaged on receipt against a 5 point check to assure they have sufficient information to progress through the DARS process (e.g. That the correct consents are in place, that the legal basis is appropriate etc.)

SLA category	Applications open at end of period			Total Closed applications since 01/02/15 (completed or rejected)
	Within SLA	Breach	Total	
Standard (14 day)	4	0	**4**	
Medium(30 day)	29	0	**29**	
Complex(60 day)	39	0	**39**	
All applications	72	0	**72**	**49**

All applications for data received since February 1st 2015 are within their SLA. A further breakdown of performance is provided in Annex A.

Reporting on progress against historic applications and SLAs is provided, via the dashboard in Annex A, to the HSCIC Executive Management Team on a weekly basis. An overview of progress, based on information supplied in the dashboard will be published on the HSCIC website on a frequent basis.

Resourcing the Permanent DARS Structure

The overall DARS process and procedures for managing data applications is developed and functional with work ongoing to further refine and improve these and recruitment to the permanent DARS structure is underway. The majority of posts for Data Applications Case Officers, responsible for processing the applications through DARS have been filled. Senior roles (AFC 8b and above) across the whole DARS structure (applications, approvals and performance management) are currently being recruited too.

In the interim, the senior roles are being covered by the special operations team, originally convened to support clearing the backlog. Establishing the permanent structure is key to ensuring not only the timely processing of applications but also that customers receive and feel they are receiving a good service.

Roll out of Data Sharing Framework Contracts

Each organisation wishing to receive data from the HSCIC is now required to sign a Data Sharing Framework Contract which sets out the overarching principles of data sharing between the organisation and the HSCIC. Each individual instance of data sharing will then be covered by a Data Sharing Agreement. The deadline for moving to the new contracts was

set as end of February 2015 and customers were extensively engaged to alert them to this date.

Roll out of DSC's commenced on 24/10/14. 464 organisations with existing Data Sharing Agreements were contacted informing them of the requirement to have a signed contract by the end of February.

As of 17/03/15:

No of organisations contacted	464*
Not required (e.g. customer no longer wishes to receive data or the DSA was for a tabulation with small numbers supressed)	220
Total contracts received back from customers	**185**
Of which: Active Contracts (e.g. signed by customer and HSCIC SIRO)	146
in progress with HSCIC (e.g. undergoing security review)	39
Outstanding Contracts (e.g. with customer (to sign or respond with further information) or with HSCIC to respond to customer query)	**59**

* The above figures represent customers who already had live agreements with the HSCIC prior to the Data Sharing Framework Contracts being introduced. They do not include customers currently applying for data who require a Contract for the first time.

Issues have been raised by organisations who for various reasons are unable to sign the contract in its current form. The HSCIC is in active discussion with these organisations to resolve these and agree a way forward.

All customers who have not yet returned a signed contract and are not in active discussion with the HSCIC have been contacted informing them of the need to supply data destruction certificates for all data that they hold.

An escalation process regarding actions the HSCIC will take if deletion certificates are not received from these organisations is being finalised.

Data Deletions

A further data cleansing exercise has been undertaken which has identified that there are 553 organisations who hold around ~2400 Data Sharing Agreements issued under the NHS IC and HSCIC prior to May 2014.

As of 13/03/15, 405 'Certificates of Data Destruction' have been received from 146 organisations. There are currently 221 requests for renewals or extensions to data. If approved, these will not require a data deletion certificate.

An outbound phone campaign has been initiated to directly contact every organisation in receipt of identifiable or potentially identifiable data. 9 fte resources have been dedicated to this work and it is anticipated, based on past experience, that it will take an average of two phone calls to identify the correct person to speak to, lasting around 3 minutes each and a further in-depth conversation outlining the requirement and resolving any queries, lasting around 30 minutes. Based on these figures, it is expected that the outbound campaign should take ~10 working days to complete.

The intelligence gathered as a result of this campaign will support the planning for completion of this work.

Owing to the age of many of the agreements issued under the predecessor organisation, the NHS IC, it is expected that there will be a number of cases where organisations may not immediately be able to identify receipt of the data if at all.

The approach for handling these is being developed along with a matrix outlining the next steps regarding HSCIC action against those who are contactable but do not return certificates. This will determine what action will be taken following the outcome of the outbound campaign.

Audit function

Audits of 4 organisations who receive or have received data under a Data Sharing Agreement have been completed and the outcomes have been published on the HSCIC website. Follow up visits are in progress with these organisations to assess their response to the recommendations made by the HSCIC as a result of the audit.

4 further organisations are currently being audited with the expectation that these will be completed by the end of April. The outcome of these audits will be published at an agreed time after this.

Development of the permanent audit function is currently under way. This includes developing the HSCIC audit policy, processes and procedures and the formal audit programme outlining the forward audit schedule.

A recruitment exercise for 4 permanent audit resources who will be responsible for carrying out the audits against Data Sharing Agreements is underway. Offers have been made against 2 of the generalist posts however 2 specialist posts remain to be filled. A second round of recruitment is planned against these posts. In the meantime, 8 HSCIC staff have

now received the appropriate training to enable them to carry out audits on an interim basis. This interim function will persist until the permanent roles are filled.

It is planned that in total, 25 audits will be carried out during 2015/16.

Secure Access to Data

A paper has been provided in Annex C outlining progress against this recommendation.

Alignment with additional HSCIC Commitments

Following the Review of Data Releases and in response to Sir Nick Partridge's recommendations, the HSCIC board put forward a programme of work for positive change. These largely align with the work carried out in direct response to Sir Nick Partridge's recommendations, however additional update is provided where there is no one-one mapping. Further details of this are provided in Annex B.

Progress against recommendations from the Data release review

The information below provides a more detailed summary of progress against each of Sir Nick Partridge's recommendations.

Recommendation 1

Recommendation	Action	Progress
1) That the HSCIC undertakes a programme of work to ensure that data has been deleted appropriately for all data releases referenced in the PwC report, where the agreement has ended.	• Issue letters to all data recipients with Data Sharing Agreements (DSA) where the agreement has ended to confirm data deletion. • Review options to support customers in deleting the data. • Confirm data deletion complete.	• Outbound phone campaign initiated on 16/03/15 with 9 fte resources dedicated to calling every organisation in receipt of identifiable or potentially identifiable data received prior to May 2014 from either the NHS IC or HSCIC. • Preparatory work for the campaign has identified 553 organisations who hold ~2400 Data Sharing Agreements • As of 13/03/15, 405 'Certificates of Data Destruction' received from 146 organisations. • 221 requests for renewals or extensions to data have been received. If releases are approved, these will not require a data deletion certificate. • Outbound campaign expected to be completed by mid April 15, at which point a clear position will be available regarding the number of instances where it will not be possible to confirm deletion (owing to the age of data, organisational and structural change). • A matrix outlining the next steps, regarding HSCIC action against those who are contactable but do not return certificates is being developed by IG. This will determine what action will be taken following the outcome of the outbound campaign. • The Business as Usual process for data deletion for data released by the HSCIC has been built into new processes and resourced from within the contact centre. These processes are active and being managed.

Recommendation 2

Recommendation	Action	Progress
2) That the HSCIC develops one clear, simple, efficient and transparent process for the management of all data releases.	• Develop approach and specification for Data Access Request Service. • Identify existing re-useable components for integration. • Transition components and implement Data Access Request Service. • Provide simple intuitive access point for customers.	• Single access point for access to data (Data Access Request Service (DARS)) established. • Work underway to ensure business areas across the organisation are following the DARS process correctly. • Programme of work underway to ensure applications for primary care data, currently overseen by GPES IAG and those with separate governance processes are managed and tracked consistently through DARS. • Recruitment ongoing for Business as Usual structure for the Data Access Request Service (DARS). All case managers have been recruited. Recruitment of management team underway. Temporary / seconded resources will continue to fill these posts until recruitment is complete. • SLAs being measured and reported on for all applications received since 01/02/15. • Backlog of data requests (those received prior to 01/08/14) cleared. Discussions are ongoing with a small number of complex cases. • 'Pre-SLA' applications received between 01/08/14 and 31/01/15 being progressed, with target date of completion by end May 15. • Webpage providing single access point for access to data being reviewed and improved. • Development underway to provide a web form to enable customers to complete applications online • A review is underway for options to facilitate online customer login and a progress tracker.

Recommendation 3

Recommendation	Action	Progress
3) That the HSCIC implements a robust audit function, which will enable ongoing scrutiny of how data is being used, stored and deleted by those receiving it.	• Identify resources to undertake audits. • Submit paper to EMT to agree approach. • Create framework, methodology and audit checklist. • Identify candidate organisations for initial audit. • Complete first wave of audits. • Develop approach and plan for full audit capability.	• Draft Audit framework and methodology developed. • Four audits completed and outcomes published on HSCIC website • Follow up meetings with these organisations underway, scheduled for completion by end April • 4 further audits underway, scheduled for completion by end April. • Recruitment for 4 permanent audit resources underway. Offers have been made against 2 generalist posts however 2 specialist posts remain to be appointed too. A second round of recruitment is planned to try and fill these posts. • The interim function will remain in place whilst this recruitment is ongoing, with parallel working on appointment to ensure smooth transition. • HSCIC is committed to carrying out 25 audits of organisations in 15/16. • The HSCIC audit policy is being developed along with processes and procedures. • The formal audit programme is being developed which when launched will provide the forward audit schedule and associated policies and processes.

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Recommendation 4

Recommendation	Action	Progress
4) That the HSCIC publishes its policy, process and governance for the release of data.	• Incorporate learning from Partridge review into development of revised policy, process and governance. • Develop and implement revised policy and process. • Develop and implement revised governance arrangements. • Publish policy, processes and governance for release of data on HSCIC website. • Refine and update processes.	• Revised single process for all data access requests has been implemented. • DARS webpages are currently being reviewed and improved to provide greater clarity around the processes and policies. • High level Data dissemination rules developed and embedded into the data release checklist, which is being used to assess applications. • 1st draft of Data dissemination policy developed and reviewed by CAG on 13th February. Comments are being impacted with further workshops at the end of March. The final policy will be released once the Care Act regulations have been published and impacted. It is expected that this will be no later than end of October 15. • Programme of communications to update customers and staff about new processes and implementation of SLAs being developed for rollout at the end of January.

Recommendation 5

Recommendation	Action	Progress
5) That the HSCIC ensures there is clear, transparent and timely decision making, via the appropriate governance for all data releases, and that all decisions are documented and published on its website.	• Develop transparent, clear process that is accessible to all users. • Document and publish all decisions from DAAG. • Recruit patient and public representatives to DAAG.	• Interim Data Access Advisory Group (DAAG) operational. Membership and frequency of meetings increased to ensure data applications are processed in line with SLAs. • DAAG recommendations published on HSCIC website. • Terms of Reference for the Data Dissemination Advisory Group (DDAG), successor to DAAG currently under review. • Data Publication and Dissemination Group (DPDG) being established to provide strategic overview of Data dissemination.

Recommendation 6

Recommendation	Action	Progress
6) That the HSCIC implements a robust record keeping approach and that the details of all data releases (including the purpose for which they are released) are made available on its website.	• Enhance and unify existing data sharing 'trackers' for short term management of releases. • Develop unified order management approach using Customer Relationship Management (CRM) system as single source of truth. • Publish quarterly Data Release register. • Complete transition to order management process across the organisation for management of all data requests.	• Single system in place and being used to management of data access applications. • Dashboard created for weekly reporting to EMT providing tracking and monitoring against progress on pre-SLA applications and performance against SLA's. • Progress on 'pre-SLA' applications reported in 'Data Insight' communication and via HSCIC website from early April. • Performance against Service Level Agreements reported on HSCIC website from early April. • 4th iteration of HSCIC data release register scheduled to be published in early April 15, covering data releases made between 30/09/14-31/12/14. • Development of automated production of the register will be linked with automating the processes for submitting online application forms, creation of DSA's etc.

Recommendation 7

Recommendation	Action	Progress

7) That the HSCIC develops one Data Sharing Agreement (DSA), which is used for all releases of data, and which includes clear sanctions for any breaches.	• Review and revise rules for Data Dissemination.
	• Develop revised Data Sharing Agreement.
	• Agree plan and approach for transition from current to revised Data Sharing Agreements.
		• Universal Data Sharing Agreement (DSA) and Data Sharing Framework Contract (DSC) rolled out. Templates published on the HSCIC website with supporting guidance.
		• Requirements from Code of Practice on Confidential information being incorporated into DSC / DSA.
		• Roll out of DSC's commenced on 24/10/14. 464 organisations with existing Data Sharing Agreements contacted informing them of the requirement to have a signed contract by 28/02/15.
		• As of 18/03/15:
		    • 185 contracts have been received
		    • 220 contracts are not required or have been cancelled
		    • 59 contracts are still outstanding.
		• An escalation process regarding actions the HSCIC will take if deletion certificates are not received from these organisations is being finalised.
		• The function for monitoring and management of Data Sharing Framework Contracts is in development.

Recommendation 8

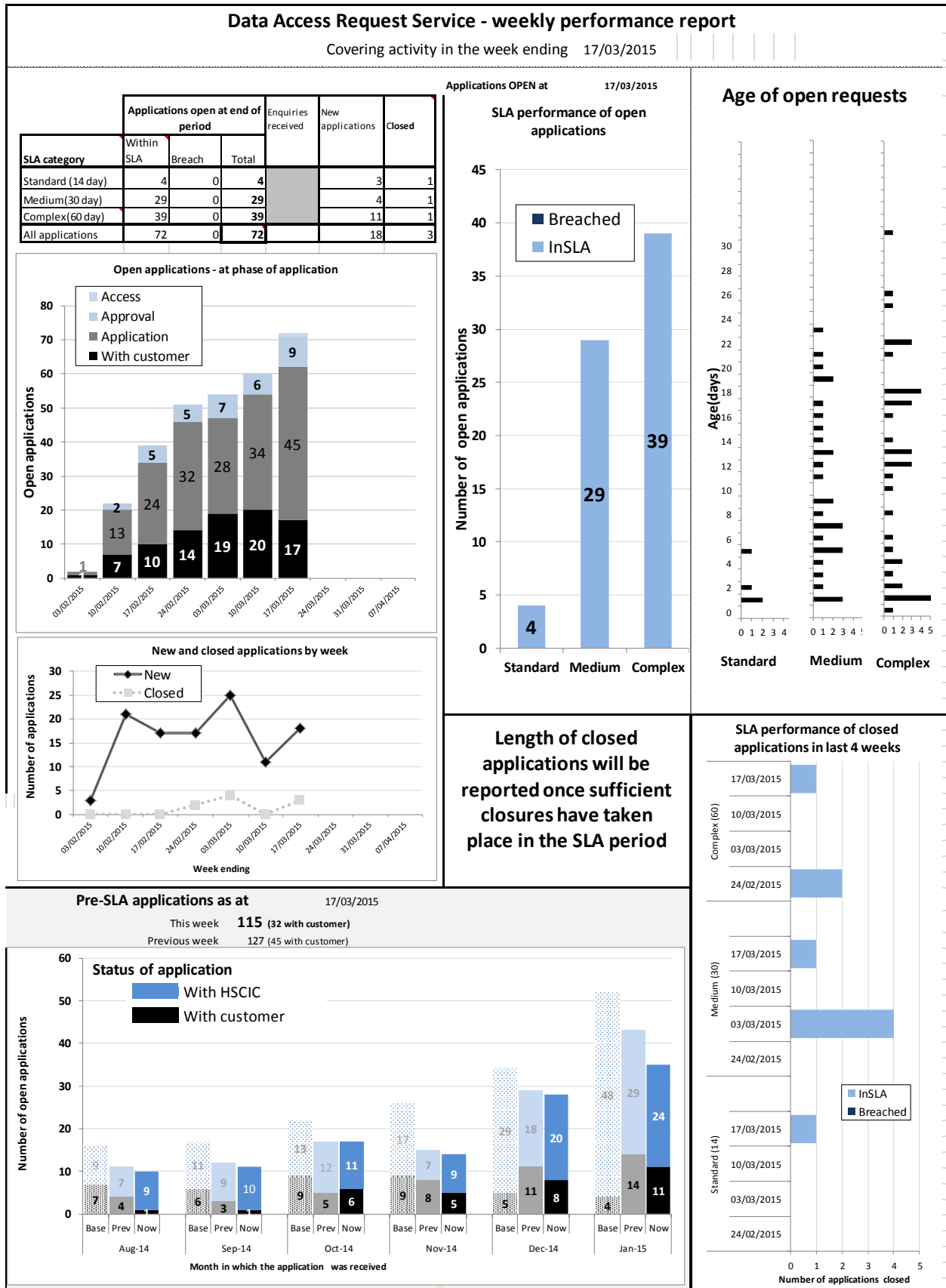| Recommendation	Action	Progress
8) That the HSCIC actively pursues a technical solution to allow access to data, without the need to release data out of the HSCIC to external organisations.	• Develop scope and identify options. • Produce and publish road-map for provision of secure data access / data lab.	• Engagement with stakeholders has highlighted the key challenge is to develop a set of solutions that enable as high proportion as possible of users of data to deliver the same benefits to health and social care as they would through receipt of a physical extract. • Further exploratory work is underway to understand these challenges. • Expert Reference Group established from a cross-section of HSCIC stakeholders. This group will be responsible for providing expert advice and review in the development of the policy and options for secure access. Meetings are scheduled for this group for April and May. • First draft or policy that determines the type of access available under which circumstances has been developed and is being reviewed by Expert Reference Group. • Discovery activity for secure access solutions will continue, influenced by the design of the policy • A secure data facility will be ready for operations by 31 March 2015 as planned. This will be available to support the care.data pathfinder stage when required. The HSCIC is also looking to use the facility to provide secure access to other datasets such as access to Hospital Episode Statistics data. • Processes for approval and access to SDF being developed. This will be managed through the DARS process to ensure alignment across the organisation. • Proof of concept for flexible public access to anonymised data has been refined and launch plans are being developed.

Recommendation 9

Recommendation	Action	Progress
9) That the HSCIC quarterly Register of all data releases includes the number of law enforcement agencies' person tracing requests processed by the National Back Office. The Register will also include all data being released under NHS IC data sharing agreements, ensuring it is providing a comprehensive account to the public of all data being shared.	• Publish number of law enforcement agencies' person tracing requests processed by the National Back Office (NBO). • Update quarterly register with data being released under NHS IC data sharing agreements.	• Data release register, incorporating number of tracing requests processed by NBO, published on 02/07/14. This register covered data releases made between 01/04/13 – 31/03/14. • 2nd iteration of HSCIC data release register published on 6/10/14 covering data releases made between 01/04/14-30/06/14. • 3rd iteration of HSCIC data release register published on 14/01/15 covering data release made between 01/07/14-30/09/14. • 4th iteration of HSCIC data release register scheduled to be published in early April 15, covering data releases made between 30/09/14-31/12/14.

Actions Required of the Board

The Board is asked:

- To note the significant progress to date.

- To accept the proposal that a closure report on the recommendations from the Data Release Review be provided at the next Board meeting, pending the outcome of the audit by the Health Group Internal Audit service.

- To accept that proposal that future reporting will be limited to specific workstreams (e.g. Audit function, Data deletions and Secure access to data) and any additional requests by the Board.

Annex A: Progress against SLA's and historic 'pre-SLA' applications

Data Access Request Service - weekly performance report

Covering activity in the week ending   17/03/2015

SLA category	Applications open at end of period			Enquiries received	New applications	Closed
	Within SLA	Breach	Total			
Standard (14 day)	4	0	4		3	1
Medium(30 day)	29	0	29		4	1
Complex(60 day)	39	0	39		11	1
All applications	72	0	72		18	3

Open applications - at phase of application

New and closed applications by week

Applications OPEN at   17/03/2015

SLA performance of open applications

Age of open requests

Length of closed applications will be reported once sufficient closures have taken place in the SLA period

SLA performance of closed applications in last 4 weeks

Pre-SLA applications as at   17/03/2015

This week   **115** (32 with customer)
Previous week   127 (45 with customer)

Annex B: Alignment of recommendations with HSCIC commitments

1. Patients and public representatives will be part of the new membership of the HSCIC's data oversight committee, the Data Access Advisory Group (DAAG). This work will be overseen by the Confidentiality Advisory Group which will gain statutory powers later in the year.

See update on recommendation 5.

2. All data agreements will be re-issued, to ensure activity is centrally logged, monitored and audited, resulting in a clear and transparent process. Decisions will be documented and published.

See update on Recommendation 7.

3. A new, strengthened audit function will monitor adherence to data sharing agreements and halt the flow of data if there are any concerns exposed. This will also monitor that data has been deleted when an agreement comes to the end. Any failure on the part of data users to abide by their agreements will entail no further release of data to them.

See update on Recommendation 3.

4. A programme of active communication to the public and patients will help bring greater clarity about an individual's right to object to their data flowing to or from the HSCIC.

The HSCIC is working with the Department of Health and NHS England, to clarify the nature and scope of the objection choice to be offered in replacement of the Type 2 objection, as previously set out within the Care.Data Programme. Communications are being planned to support this.

5. A list of all active data sharing agreements will be published in the HSCIC quarterly register, including 14 which originated in the NHS IC. Numbers of all people tracing requests by law enforcement agencies will also be included.

See Recommendation 9

6. Working with partners through the National Information Board we will begin a public consultation and vision for a new national collection strategy for health, public health and social care data and report by May 2015 on its findings.

The need for a new data strategy is a key theme in the new HSCIC corporate strategy, which will be published for consultation at the end of January. The HSCIC continues to work through the NIB and the relevant workstreams which are developing the plans for implementing the commitments in the NIB Framework for Action. The workstreams expect to produce more detailed plans by February 2015.

7. The HSCIC will take forward its new responsibility to oversee NHS data security across the health and social care sector, to ensure best practice is followed and the most up-to-date technology is employed to protect patients.

The HSCIC is currently managing a project commissioned by the Secretary of State which is looking specifically at Data Security across the wider health system. Over 40 tests are planned, or have been completed, in a variety of different organisation types and HSCIC will assess the results of these tests over the coming months. The output of these assessments will inform and drive the development of new data security standards, architectures and technology adoption as outlined in the NIB Framework for Action.

HSCIC has also now received approval from the Cabinet Office National Cyber Security Programme to run a number of national level projects until March 31st 2016 in support of innovative approaches to Cyber Security and incident management.

8. The HSCIC will plan a new 'data laboratory' service which will protect the public's information by allowing access to it in a safe environment with HSCIC managed networks and facilities.

See Recommendation 8 and appendix C.

9. The HSCIC will work towards the externally assessed, highest industry standards of ISO27001 for data security and ISO9001, for data management, as part of its efforts to build public confidence.

A Management Systems team has been established responsible for leading this business change and providing assurance (through the recently established Quality Council) that the HSCIC is making progress for the adoption of ISO 9001 and ISO 27001 (Information

security).

Implementation has commenced, with all areas across the organisation requesting an initial baseline internal audit by 31st December 2015. Implementation will be phased across the organisation, with some areas having already achieved certification to ISO 9001.

Recruitment has commenced for permanent internal auditors to support the implementation of the ISO standards. This will be supported by training for ten part-time auditors drawn from existing HSCIC resource who will provide a minimum of two audits per annum. It is expected that these resources will be trained and ready to audit by 31st March 2015.

It is intended all areas of HSCIC will be certified to ISO 9001 and 27001 by March 31, 2017.

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Annex C: Secure Data Access

Author – Richard Irvine

1   Background

In his review of data released by the NHS Information Centre, one of Sir Nick Partridge's nine recommendations was: ***'That the HSCIC actively pursues a technical solution to allow access to data, without the need to release data out of the HSCIC to external organisations.'***

Good progress has been made on elements of this recommendation.

A secure data facility will be ready for operations by 31 March 2015 as planned. This will be available to support the care.data pathfinder stage when required. The HSCIC is also looking to use the facility to provide secure access to other datasets such as access to Hospital Episode Statistics data. Candidate organisations, with appropriate approvals, are being selected to be the first customers of the service. This early activity will help to refine and enhance our supporting processes. A complete evaluation will take place beyond pathfinder stage to determine if we continue the service at the HSCIC, or seek an alternative approach.

A proof of concept for flexible public access to anonymised data has been refined and launch plans are being developed (see appendix A)

Options for different types of remote access to pseudonymised data are being considered and further details are set out in appendix B.

However, a central challenge was highlighted in feedback to the consultation exercise and at the 5th December stakeholder event. This is that a large proportion of customers do not expect to be able to realise the same benefits to health and care accessing data through a technical solution as they would through receipt of an extract.

This challenge needs to be met by a two-fold approach:
1. Design of a policy that determines which type of access will be available under which set of circumstances that minimises the transfer of data through extracts.
2. Development of a set of solutions that enables as high proportion as possible of users of the data to deliver the same benefits to health and care as they would through receipt of a physical extract.

To address both 1) and 2), a more focussed phase of stakeholder engagement has commenced. Whilst recommendation 8 provides the mandate, it is possible that we may, working in partnership with our customers, determine an alternative approach to describe our end goal.

2 Progress

2.1 HSCIC Strategy

Further exploratory work has commenced to understand the challenges relating to secure data access as described in Sir Nick Partridge's recommendation. This discovery activity will help to describe the HSCIC's new service model and will have implications for the current data access request service.

Hand-in-hand with this will be the development of policy around the different types of data access that organisations would be allowed under different circumstances, which will also need to respond to the type of data being requested.

Secure data access routes will be developed, supported by the Data Services Programme, to meet a variety of customer requirements, with the assumption that a customer will get the minimum access to meet their needs. Note that it is highly likely that some customer needs and associated benefits to health and social care will still only be met through physical extract, but this will need to be fully tested.

Release of public top-level HES data, combined with a way that analysts can interrogate using a corporate tool, would offer up a potentially richer set of open data – this would bring us into line with developments in other government departments.

2.2 Stakeholder Engagement

A programme of engagement and further consultation has been established to socialise, further develop and finalise this policy and associated secure access options. At the heart of this engagement is the need to exploit the benefit of our information assets and to meet the needs of our customers, whilst ensuring that access is secure and data is kept safe.

In order that the programme of consultation and engagement is robust, a focussed reference group has been brought together from a cross-section of the HSCIC's stakeholders. The starting point was a re-purposing of the care.data Expert Reference Group, expanding its role to cover these requirements in addition to those of care.data. The Expert Reference Group is made up of subject matter experts relating to secure access and the group meets on a frequent basis.

The overall mandate of this reference group, alongside care.data activity, is in an advisory capacity to consider draft policy and options for secure access and to provide expert advice and guidance accordingly. This reference group makes recommendations to the HSCIC's Executive Management Team, via the Director of Benefits and Utilisation. This helps to ensure that our customers' needs are understood and articulated, and that limitations and risks are equally understood, articulated, and have appropriate mitigation.

The group contains membership that will add value to this agenda and also contains individuals, particularly from the research community, who hold specific director-level roles that will assist in taking forward solutions at pace.

2.3   Financial Implications

There are no financial implications relating to this activity at this stage.

3   Risks

A formal risk register is maintained for this programme, which provides further detail, but in summary the major risks that will be resolved by this proposal are:

- that the scope for the HSCIC's future secure data access services remains unclear;
- that, whilst customer insight has been sought in relation to secure data access, further activity is required to align delivery to a more strategic fit that also meets our stakeholder's needs; and
- that there are limited access options available to reduce bespoke requests
- that HSCIC risks falling behind other departments in developing open and public data

4   Next Steps

Early feedback demonstrates that the Expert Reference Group is broadly supportive of the draft policy, although a key observation is that the HSCIC is attempting to describe and consult on solutions rather than understand what problems it is trying to address. This is being addressed in advance of further detailed discussion at the start of April.

The Group noted that, for any change in HSCIC's approach to be successful, a behavioural shift will be required by customers of the service and this will require time. Equally organisations have developed complex technical solutions, at some expense, and therefore adequate transition will be required to ensure that flexibility and a sense of control can be maintained.

A further challenge will be introducing new policy and inviting our customers to embrace this at a time when stakeholder confidence in the HSCIC is perhaps not at the level it could be, although the group did note recent progress in addressing the backlog. The Expert Reference Group suggested that if new policy is too restrictive then organisations may identify alternative routes to accessing datasets.

The Expert Reference Group will next meet on 1 April and then again on 28 April and 22 May. The Group are supportive of the need to move this activity at pace, but at the same time understand that focussed effort is required if we are to achieve an acceptable balance.

Discovery activity for secure access solutions will continue, influenced by design of associated policy and the Expert Reference Group will provide consultative activity in this area.

Appendix A: HES Admitted Patient Care proof of concept

A new data asset has been created, consisting of already-published annual HES data, concatenated into timeseries which enable trending and drill-down. The following cuts of data have been assembled:

- Admitted Patient Care, by Provider, 5 years (2008/09-2012/13)
    - o <u>Dimensions</u>: Sex, Age, Diagnosis, Procedure, Cause.
    - o <u>Metrics</u>: Admissions, Episodes, Bed Days, Wait Time, Length of Stay.
- Admitted Patient Care, by Procedure, 16 years (1998/99-2013/14)
    - o <u>Dimensions</u>: Sex, Age, Admission Method.
    - o <u>Metrics</u>: Admissions, Episodes, Bed Days, Wait Time, Length of Stay.

The following methodology was used in preparation of the data asset:

a. All data taken from already-published spreadsheets, not from original HES data

b. All suppressions in those spreadsheets are maintained

c. All totals and subtotals are pre-aggregated

As a result, there are **no new numbers**: all numbers in this data asset have already been published by HSCIC.

Appendix B: Data access solutions - areas of progress to date

Following the Partridge Report, the HSCIC quickly identified three themes relating to secure data access and have been exploring these with the focus to support the need to control data assets, whilst at the same time ensuring flexibility of the data access service to our customers. These themes are as follows:

1) Secure Data Facility
2) Federated Hierarchy
3) Secure Remote Access

There is a fourth strand relating to access of open and public data, which essentially enables customers of the HSCIC's data to serve themselves with anonymised data instead of needing to request bespoke work.

It is important that public and open data are referenced as part of the HSCIC's activity in relation to secure data access due to the impact that request handling has on the HSCIC's current services. As we apply more energy to achieving a channel shift away from a bespoke request service to a surfacing of aggregate information, our customers will benefit from more information being made publicly available and also a positive impact on the data access request service for data that needs to be handled securely. The HSCIC will focus on HES data initially, which is subject to the most requests for bespoke tabulations and most Parliamentary Questions, and a 15-year time series of top-level HES data has been created.

Significant progress has been made in identifying requirements for the 4 options described above, particularly the Secure Data Facility (SDF). Commissioning of the SDF represents the first stage in developing the HSCIC's new service model. Throughout planning stages for the SDF, our customers have been consulted and feedback has helped to shape this initial delivery.

But this leaves a gap in the middle and has demanded the need to consult with stakeholders regarding the challenges noted before we can plan specific delivery. Any approach will need to include the noted development and communication of an overarching policy outlining the criteria by which the different options for accessing data in a secure environment will be applied. With this in mind it is likely that the HSCIC will develop a set of incremental products that meet a progressively larger set of customers' needs, which after a period of user engagement, will reduce the need for extracts in certain circumstances.